MINUTES
of the
FOURTH MEETING
of the
LEGISLATIVE HEALTH AND HUMAN SERVICES COMMITTEE

September 4-5, 2013
Barbara Hubbard Room, New Mexico State University
1810 E. University, Building 284
Las Cruces

September 6, 2013
Skeen Library, New Mexico Institute of Mining and Technology
Socorro

The fourth meeting of the Legislative Health and Human Services Committee (LHHS) was called to order by Representative James Roger Madalena, chair, at 9:10 a.m. on Wednesday, September 4, 2013, in the Barbara Hubbard Room at New Mexico State University (NMSU) in Las Cruces.

Present
Rep. James Roger Madalena, Chair
Sen. Gerald Ortiz y Pino, Vice Chair
Rep. Nora Espinoza
Rep. Doreen Y. Gallegos
Sen. Gay G. Kernan
Rep. Terry H. McMillan (9/4, 9/5)
Sen. Mark Moores
Sen. Benny Shendo, Jr. (9/4, 9/5)

Absent

Advisory Members
Rep. Phillip M. Archuleta (9/4, 9/5)
Sen. Sue Wilson Beffort (9/4, 9/5)
Sen. Craig W. Brandt
Rep. Nathan "Nate" Cote (9/4, 9/6)
Rep. Miguel P. Garcia
Rep. Sandra D. Jeff
Sen. Linda M. Lopez (9/6)
Sen. Cisco McSorley
Sen. Bill B. O'Neill (9/5)
Rep. Paul A. Pacheco (9/6)
Sen. Mary Kay Papen (9/4, 9/5)
Sen. Nancy Rodriguez (9/6)
Sen. Sander Rue (9/6)
Rep. Edward C. Sandoval

Sen. Jacob R. Candalaria
Sen. Daniel A. Ivey-Soto
Sen. Lisa A. Torraco

Sen. William P. Soules (9/4, 9/5)
Rep. Elizabeth "Liz" Thomson

Guest Legislator
Sen. Howie C. Morales (9/6)

(Attendance dates are noted for those members not present for the entire meeting.)

Staff
Michael Hely, Staff Attorney, Legislative Council Service (LCS)
Shawn Mathis, Staff Attorney, LCS
Rebecca Griego, Records Officer, LCS
Branden Ibarra, Intern, LCS
Nancy Ellis, LCS

Guests

The guest list is in the meeting file.

Handouts

Handouts and other written testimony are in the meeting file.

Wednesday, September 4 — NMSU

Welcome to NMSU

Following committee and staff introductions**,** Garrey Carruthers, president of NMSU and former governor of New Mexico, welcomed committee members and guests to Las Cruces. Governor Carruthers humorously described his institution as "The Yale of the Yuccas". "This is a great university", he said, mentioning NMSU programs in agriculture, the sciences and public health, among others. There should be a three-tier formula for funding of higher education in New Mexico, Governor Carruthers said: one for science universities; one for comprehensive universities; and one for technical training universities. The University of New Mexico (UNM) and NMSU are collaborating on a public health initiative addressing drug use, alcoholism and obesity in the state. Last year, NMSU received a one-time matching fund endowment of $20 million from the legislature. Governor Carruthers stated his intention to ask for another one-time $20 million appropriation that he is certain NMSU has the ability to match.

NMSU Doctor of Nurse Practitioner Program

Dr. Pamela Schultz, Ph.D., School of Nursing, NMSU, told committee members that in response to new requirements that nurse practitioners have doctoral degrees in order become certified, NMSU has made changes to the master's degree in nursing curriculum. For practitioners already certified, there is a master's-to-doctorate track, and new students will be on a bachelor's-to-doctoral track, Dr. Schultz said. There are over 200 programs like NMSU's throughout the country, with many more poised to begin. In response to a question from a

committee member, Dr. Schultz said that while there is some grandfathering of current providers, it will take time for the work force to accept these new changes. In the long term, these practitioners will deliver better care, she said. Another committee member asked about the increased time and costs associated with attaining a doctorate. The committee member was concerned that the requirement of a doctoral degree flies in the face of efforts to expand the health care work force. Dr. Schultz replied that NMSU is still admitting approximately the same number of students at the baccalaureate level. "We've all heard of the nursing shortage", she said, and the greatest shortage is among those who are qualified to teach, i.e., those with a doctorate. Asked by another member if the School of Nursing needs additional resources from the legislature, Dr. Schultz said that the school cannot admit all who are qualified for the doctoral program, thus additional funding could help increase those numbers.

Minutes Adopted

A motion was made to adopt the minutes of the July 1-3, 2013 meeting held in Albuquerque and Rio Rancho. The motion passed without objections.

Child Abuse Prevention Panel

Shelly A. Bucher, L.M.S.W., and Esther Devall, Ph.D., certified family life educator, Family and Consumer Sciences Department, College of Agriculture, NMSU, provided a PowerPoint presentation to the committee entitled "Prevention of Child Maltreatment" (see handout).

Child maltreatment is defined as any act of commission or omission by a parent or other caregiver that results in harm, potential for harm or threat of harm to a child, Ms. Bucher said. Acts of commission include physical, sexual or mental abuse. Acts of omission include physical, emotional, medical or educational neglect; failure to supervise; and exposure to violent environments. Child maltreatment is a huge public health issue, Ms. Bucher said, citing 2008 figures from the Centers for Disease Control and Prevention indicating a $124 billion impact for that year alone. The long-term effects of child maltreatment include smaller brains, learning disorders, juvenile delinquency, suicide, higher rates of sexually transmitted diseases and alcohol and drug abuse. In New Mexico, the average reported incidence of child maltreatment is 12 per 1,000 children, she said, which is higher than the national average of 9.9 per 1,000 children. Under New Mexico law, every person is mandated to report child maltreatment, Ms. Bucher said.

Dr. Devall described risk factors for child maltreatment: poverty, young maternal age, single-parent status, isolation, substance abuse, depression and lack of understanding of child development. Prevention is far more effective and less costly than treatment and involves education and family support, especially for families with risk factors for child maltreatment. Media campaigns increase public awareness, and parent education, nurse home visits and parent support groups are effective ways to combat child maltreatment.

NMSU is the southwest regional site of the National Child Protection Training Center, Dr. Devall said. Through training, education, awareness, prevention and advocacy, the center

serves child-focused professionals working in New Mexico, Arizona, West Texas and Southern California and students whose careers will bring them into contact with children. State-of-the-art training and education help prepare current and future professionals to more effectively intervene in cases of child abuse and neglect (see handout). The training center provides evidence-based training and technical assistance to prosecutors, law enforcement officers, child protection workers, therapists, advocates and others who work with children. Also through the training center, child advocacy studies (CAST) is being offered at NMSU to students majoring in disciplines that will involve interaction with children. NMSU's CAST is one of only two programs in the western United States, providing an 18-hour interdisciplinary undergraduate minor in family and child welfare policy.

Dr. Devall urged legislators to restore funding of $1 million for intensive, evidence-based parenting classes. "I'm tired of New Mexico being last in everything", she said. "I want New Mexico to be first."

Jared Rounsville, director of the Protective Services Division (PSD) of the Children, Youth and Families Department (CYFD), told committee members that child abuse presents complex and challenging issues. The PSD responds to 16,000 to 18,000 reports annually. One thousand eight hundred children are in foster care in the state. Mr. Rounsville described several current division initiatives, including a media campaign to educate parents about not leaving their child in a hot car and ongoing development of a short code (#SAFE) to connect to a phone line, staffed 24 hours per day, seven days per week, for immediate reporting of suspected child maltreatment.

Yolanda Berumen-Deines, secretary of children, youth and families, said that child abuse is generational and multilayered and includes many risk factors. Destructive experiences impact the developing child's brain, increasing risks for emotional, behavioral, academic, social and physical problems throughout life, Secretary Berumen-Deines said, and she referred to extensive research conducted by psychiatrist Dr. Bruce Perry, an international authority on children in crisis. The CYFD is very supportive of family wellness education, she said. Being aware of the issues, parents and child care providers can be trained on how to interact with the child to heal those damaged connections, Secretary Berumen-Deines said.

Questions/Concerns

A committee member expressed the opinion that foster parents have the hardest job in the state and that the CYFD must continue to support them and expand foster parent training. Secretary Berumen-Deines said that the agency has initiated mandatory statewide training of foster parents based on a neurosequential model of therapeutics developed by Dr. Perry. She said that there has been a "culture change" within the CYFD in the past several years and that it is becoming more decentralized and is utilizing teams in each office.

Another member asked if calls reporting abuse are accepted anonymously. Mr. Rounsville responded that anonymous calls have always been accepted, but the agency prefers to

be able to identify the caller if there is a need for follow-up. A member told Secretary Berumen-Deines that she has received calls from several adoptive parents regarding the need for services in their area, and there are none. They need to be supported, the member said. Other concerns addressed by committee members included the efficacy of the statewide citizen review boards, which are charged with providing monthly monitoring of CYFD cases, and warnings about the increase in the use of multiple psychotropic drugs in children.

The high vacancy rate of child protective service workers — as many as 150 positions, or 15 percent — is of great concern to another committee member. He asked if there have been any steps taken to try to fill these positions. Recruiting is the challenge, Secretary Berumen-Deines responded. The agency has been working with NMSU and UNM to encourage social work students to consider joining the PSD, which also is seeking approval for salary adjustments in order to pay more to recruit these positions. The challenge in frontier areas has been to get qualified persons on board who will actually stay, she said.

Accelerated licensing of new agencies recruited from Arizona concerned another member, who is a licensed New Mexico provider herself. Why not put New Mexico practitioners on the fast track for licensing, as well?, she asked Secretary Berumen-Deines. Normally, this is at least a 120-day process. The subject of increased penalties for abusers was brought up by another member, who noted that Secretary Berumen-Deines had spoken in favor of that. In certain areas where the actions of a person permanently impair, or result in the murder of, a child, there is a basis for greater punishment, Secretary Berumen-Deines said. Certain individuals no longer take responsibility for their behavior or for the consequences, she said, and a higher consequence is appropriate for some conduct.

There was extended discussion among committee members of reporting protocol and requirements for suspected child maltreatment, which also is the subject of a proposed series of programs at the National Child Protection Training Center at NMSU.

Home visitation of low-income, first-time mothers — 70 percent in New Mexico are on Medicaid — was not supported by the CYFD to be a reimbursed service, another member noted, and why not? Secretary Berumen-Deines said she would be willing to discuss this further, but she would rather argue for extended assessments for trauma than for home visits.

Vincente Vargas of the Cooperative Extension Service at NMSU told committee members of a current $394,000 request from the extension service for funding of rural health programs, including several for child protection and family wellness.

Public Comment

Tina Olson, executive director of New Mexico's Citizens Commission on Human Rights, urged committee members to examine the overuse of psychotropic drugs in children. Many of the increasing numbers of children diagnosed with attention deficit hyperactivity disorder (ADHD) are exhibiting nothing more than normal behavior, she said. In New Mexico, children

as young as three years are being put on strong drugs "for mental disorders". Children are the future of New Mexico, Ms. Olson said, and public outlets are needed to educate residents on the dangers of these drugs.

Dr. Jody Kinkaid, a practicing naturopath and former holistic veterinarian, told committee members that maternal nutrition is very important. In veterinary medicine, an animal missing even one meal post-birth can result in brain damage, he said. Conventional medicine treats the human brain with medication, Dr. Kinkaid said, whereas the real problem is the failure to recognize mind-body-spirit connections. Drugs depress cognitive function, and parents need to be informed of all side effects of psychotropic drugs and should not be coerced to medicate their children.

Tour

Committee members and LCS staff departed in NMSU vans to tour the Reduced-Gravity and Biomechanics Lab, with a presentation by Ou Ma, Ph.D., P.E., College of Engineering, and Robert Wood, Ph.D., professor and academic head of human performance in the Dance and Recreation Department at NMSU.

Lunch was provided by the university, and a presentation by faculty from the College of Engineering followed. Speakers were introduced by Ricardo Jacques, dean of the college, and included Anthony Hyde, Ph.D., director of the Manufacturing Technology and Engineering Center, Patricia Sullivan, assistant dean of the college, and Cynthia Bejarano, Ph.D., director of the College of Arts and Sciences at NMSU.

Concerns Regarding Children and Psychotropic Medications — Senate Joint Memorial 44

Tony Stanton, M.D., has spent many years teaching psychiatry and working in a program with developmentally disabled children. Dr. Stanton said it became very clear to him that he was being asked to medicate children for behavioral problems. "I came away with two questions: What has happened to this child up to this point, and who can we identify who could be helpful to this child?"

Fred Baughman, Jr., M.D., a psychiatrist and child neurologist, described the history of ADHD, beginning in the 1970s, as one driven by drug companies with a profit motive. In early advertising, the phrase "may be caused by chemical imbalance" was used, and that was the start of the chemical imbalance theory. Heavy marketing reinforced the theory, Dr. Baughman said, and over time, chemical imbalance became accepted as fact. "There is no such disease", he said. It is a total fraud, he said, and it has never been validated as a cause of ADHD, whose treatment almost always includes medication.

Dr. Baughman cited a 1988 National Institutes of Health review of 13 brain scans of children who had been on long-term treatment with amphetamines (including Ritalin and Adderall), which showed a 10 percent brain shrinkage. Upon this basis, it was concluded that ADHD was a disease. In 2003, it was determined that the shrinkage noted in the brain scans was

due to amphetamine exposure, he said. Many providers today believe that chemical imbalance is the cause of many disorders, and they resort to drugs for treatment.

The frequency of strokes and sudden cardiac deaths caused Canada's equivalent to the federal Food and Drug Administration to ban Adderall, but the U.S. military continues to put soldiers on antipsychotic drugs, and they are dying in bed, Dr. Baughman said. Antispychotics more than double the rate of sudden cardiac deaths, he said, and their long-term effects on children have never been studied. In the U.S. today, between seven and 10 million entirely normal children have been put on these dangerous drugs — which are, essentially, "speed", he said.

Dr. Baughman also spoke of the almost universal lack of fully informed patient consent from parents for the use of these drugs in children. In the foster care system, 50 percent to 75 percent of children are on psychotropic drugs, he said, and sometimes in unconscionable combinations. Each label, each drug, says to the child, "I am not normal".

Questions/Concerns

One committee member said she had personal experience with being pressured to start a child on drugs. "When you are being told your child has ADHD, they don't even talk to you about behavior modification", she said. Dr. Baughman reiterated his opinion that emotional or behavioral problems do not constitute a disease. Asked by another committee member if migraine headaches is a disease, Dr. Baughman responded that there are scientific studies using scans where blood-flow images and other physical markers demonstrate this physical condition. A member asked whether lower back pain is a disease. Dr. Baughman said that it is not a disease per se, it is a symptom of a condition. When asked whether autism is a disease, Dr. Baughman responded that "autism" is an indefinite term, not a specific disease. It describes a pattern of behavior. The member expressed disagreement with Dr. Baughman's opinions.

Psychiatry has spread the chemical imbalance theory, Dr. Baughman said, and psychiatrists are violating informed consent when they drug children by suggesting that there is brain disease. Asked by a member if he felt consent should be written, Dr. Baughman said yes. Dr. Stanton added his opinion that psychiatry has been led down the path to evaluate symptoms, but he feels it is crucial to look at the entire life of the child.

Another committee member told Dr. Baughman that, having heard the testimony, he felt there is great disagreement, and it is inaccurate to paint all psychotropics for all ages with such a broad brush.

Local Efforts to Examine Pediatric Psychotropic Prescribing

George Davis, M.D., director of psychiatry at the CYFD, said he was going to segue the conversation to his own area of interest: trauma (see handout). Dr. Davis said he agrees with a committee member's comment that often trauma is being treated with psychotropics. There is a higher use of these drugs in the Medicaid population, and higher yet (13 percent to 45 percent) in

children in foster care, he said. Their use is higher among males (19.6 percent) than females (7.7 percent). Since psychotropic use increases dramatically in foster care, it is clear that the drugs are being used to medicate environmental stressors, poor attachment and neglect/abuse issues, Dr. Davis said. Pressure to "simply prescribe" comes from managed care, limited time and resources, ease of maintenance and to reduce dangers to self and others.

There are side effects for psychotropic drug use, Dr. Davis told the committee, including sedation, agitation and gastrointestinal and metabolic disturbances, and their use implies misdiagnosis and indicates a lack of alternative therapeutic services. It also pushes a system toward warehousing, he said, and sets a low standard where the primary aim is sedation or deescalation.

In 2011, Congress passed the Child and Family Services Improvement and Innovation Act, which requires states applying for federal child welfare grants to establish protocols for appropriate use and monitoring of psychotropic medication in foster children, Dr. Davis said. New Mexico has begun work on it own plan, including development of "red flag criteria" — children age five years and under on any psychotropics, children on five or more psychotropics and children on two or more psychotropics from the same class (see chart in handout). Monitoring was mandated in the state's contract with OptumHealth, and letters of concern were sent to some prescribers. The new contract with Centennial Care will result in improved data collection and direct review by the CYFD and UNM child psychiatrists, he said.

David Mullen, M.D., medical director, Child Psychiatric Hospital, UNM Hospital, said psychotropic treatment sometimes has unacceptable side effects, and the effects of long-term use are not known. Children who present with serious problems — hyperactivity, profound depression, etc. — deserve some help, and those are reasons to use medications. But, he said, there definitely is overuse, and the profession is not speaking about it with one voice. Dr. Mullen teaches multifold intervention, and psychotherapy may be first, he said. "There is pressure on our profession to prescribe and undue pharmaceutical influence in what we do."

Careful interviews of all parties, including caretakers, are necessary before prescribing medication to children, Dr. Mullen said, in order to consider possible medical problems and establish an indication of why prescribing is the best benefit. Dr. Mullen prefers the lightest possible touch, starting low (in dosage), going slowly and continuing to monitor the child.

Questions/Concerns

Several members asked if there should be tracking in the prescription drug database or requirements of a prescriber before the presciber writes a prescription for a child. A member asked what methods California and Texas used to reduce psychotropic prescribing. Dr. Mullen said he will send the committee information about efforts in those states. Another member asked if written consents would help. Dr. Davis said yes, and Dr. Mullen agreed that it is reasonable, but he was uncertain about its impact. Dr. Davis said that written consents should advise of other alternatives to psychotropic drug use, such as counseling or therapy. Further discussion on

methods of prescription data mining prompted a member to say he is considering introducing a memorial at the next legislative session.

Another member commented on "more than four" drugs being prescribed concurrently to a child. "Isn't this over the top?", he asked. Dr. Davis said if he sees a child on an antipsychotic, a depressant, a stimulant and something for sleep, this profile always means that the child has been abused. When a committee member asked who is doing the prescribing, Dr. Davis said that national data indicate most of the prescribing is being done by pediatricians.

The committee recessed at 5:40 p.m.

Thursday, September 5 — NMSU

The meeting reconvened at 9:15 a.m. Representative Madalena announced a change in the agenda: continuing care communities, scheduled for 10:30 a.m., was canceled.

Prescription Drug Pricing

In a presentation about extreme drug price fluctuations (see handout), Dale Tinker, executive director of the New Mexico Pharmacists Association, first described to committee members a series of groups that are behind every pharmacist/patient transaction. Pharmacy benefit managers (PBMs) are the contractors between pharmacies and insurance providers, with cost containment as a basic component. PBMs set the price that pharmacies will be reimbursed for dispensing prescriptions. This payment includes the cost of the medication plus a dispensing fee. Insurance programs use a tool called the maximum allowable cost (MAC) pricing to control costs of generic medications. PBMs find the cheapest generic drug to establish a MAC price, but they do not disclose the name of the drug or where it can be found. It may not be available locally or from that particular pharmacy's wholesale supplier. But the biggest problem, Mr. Tinker said, is that manufacturer price increases can be dramatic and frequent, and the jump may not be reflected in MAC pricing for several weeks. When prices increase but reimbursement does not, the pharmacy suffers the loss.

PBMs are not licensed in New Mexico, Mr. Tinker said, and while some of the very large ones are well known, there often are mergers, and many smaller ones are unknown. PBM contracts are complex legal documents, he said, and the pharmacy is in violation of its contract if it does not accept the established reimbursement, even when it is below cost. PBMs do not disclose the cost basis of their MAC pricing, do not respond to price fluctuations and do not allow a mechanism to address pricing disputes in a timely manner, he said. Six states have passed legislation to regulate PBMs. On behalf of the pharmacist members of his organization, Mr. Tinker asked legislators to craft a bill requiring licensing of PBMs through the Office of Superintendent of Insurance.

Ken Corazza, owner of Medicine Chest Pharmacy in Albuquerque and chair of the New Mexico Poison Control Board, brought copies of receipts for committee members to see as

examples of enormous jumps in the costs of generic drugs — some as much as a 3,000 percent increase from his last order. "This is almost unbelievable", Mr. Corazza exclaimed. "It is pure greed." When the patient comes to fill a prescription, that price jump becomes a big problem at the counter, he said. Sometimes, the patient just walks away, deciding not to take the drugs. This is not a sporadic hit-and-miss process, he said, but rather it appears to be a conspiracy. Often, all companies that make a particular drug have the same kind of price increase at the same time. Some of these drugs have been on the market for 20 years; they are not new or recently developed. These price spikes are not just in New Mexico but are nationwide, Mr. Corazza said, and he described himself as a pharmacist making a 911 call for everyone to be mindful of what is happening.

Jason Parrish, Pharm.D., director of retail pricing for Express Scripts, said that MAC price lists are developed by each individual payer. There has not been much price fluctuation recently in brand products, he said, but fluctuations in generics have been wide-ranging, impacted by daily changes in the marketplace. "We are in the same boat when the prices come out, we're facing the same challenges", he said. In an effort to help limit unfavorable impacts on pharmacies, Express Scripts has set up an online appeal process for pharmacies.

David Root is director of state government affairs for Prime Therapeutics, a PBM that is owned by Blue Cross Blue Shield of New Mexico. Prime Therapeutics administers benefits for New Mexico's Medicaid clients, and, Mr. Root said, it has saved $5 billion for the state. PBMs are not manufacturers, Mr. Root explained, and do not make drugs or set wholesale or retail prices. Prime Therapeutics uses three national wholesale compendiums to generate its MAC list. Tinkering with MAC pricing in New Mexico will have an impact on the payers, he warned, including Medicaid, employers and whoever else offers benefits. Prime Therapeutics has set up an appeals process and provides a manual so the pharmacist understands the mechanism for appeal, he said. Pharmacists do not make a profit on every drug they sell; the MAC is like a basket of different drugs that hopefully will generate a fair return for pharmacies overall. "We are the adjudicators of the process, but we do not set up or design that program for public and private payers." Prime Therapeutics' goal is to maximize health care dollars, Mr. Root said. "We do not want to drive pharmacies out of business."

Questions/Concerns

A committee member stated that the member was "more confused now than I've ever been" by the panel's testimony. "How does a drug go from $30.00 one month to $750 the next?" Generic drugs are therapeutically equivalent to brand name drugs, Mr. Root said. Price increases of older generic drugs may be because there are not a lot of manufacturers producing them, or because the generic drug actually has become the only one on the market — an "orphan" drug. This is the way the marketplace works, he said. "How do we justify these huge increases? We do not", Mr. Root said. "It is not justified, and we have to buy at those prices, too, but the PBMs have nothing to do with this."

There are laws in other states that require that if a drug price goes up, it has to be updated

in the MAC pricing within seven to 10 days, said Mr. Corazza. The Medical Assistance Division of the Human Services Department (HSD) really needs to look into what is happening, because, in his opinion, it is absolute greed on the part of the manufacturers, and it is going to impact the Medicaid budget.

"I'm a little concerned that we need to have a third party at the table — the manufacturers", said another member. Mr. Hely confirmed that he had invited representatives from the Generic Pharmaceutical Association to attend today's meeting but had received no response.

In a proposal to regulate PBMs, manufacturers are not being addressed, a committee member noted. "You are right", said Mr. Tinker. Nonetheless, it is time to set up a platform where pharmacies — most of which operate on a two to three percent margin — can be properly reimbursed. "How to solve the problem of greed, I don't know", said Mr. Tinker. This is not a market-based industry, observed another member. What if we eliminated the middleman? The burden then would be on the insurance industry; right now, it is insulated. Another member asked why Walgreens and CVS are not complaining. They are just as concerned, Mr. Tinker said, but because they warehouse inventory, it can be weeks before they are impacted by price spikes.

Members also discussed the public safety impacts on patients who cannot afford their co-pays and walk away without their prescriptions or self-medicate with other drugs.

"What happens when a physician is denied a prescription?", another member asked. Mr. Tinker explained that the payer has a benefit design, a formulary or authorization requirement, and, in those instances, the PBM is the messenger that tells the pharmacist that the prescription is denied. Plans may adjudicate their own appeals or have a separate entity that adjudicates appeals. If the physician is e-prescribing, he or she may find out immediately while the patient is still in the office that there has been a denial of the chosen drug.

A member asked Senator Ortiz y Pino about the fate of last year's Senate Bill (SB) 360. It passed all senate committees, Senator Ortiz y Pino said, but never had a hearing in the house. It got put aside because the New Mexico Health Insurance Exchange was a priority. Last year, the Insurance Division of the Public Regulation Commission received many consumer complaints on drug price increases, and major PBMs and the New Mexico Pharmacists Association worked collaboratively on this, he said. Asked if SB 360 should be resurrected, Senator Ortiz y Pino said that it might not address MAC pricing concerns. Licensing PBMs and requiring similar procedures for uniform MAC repricing that would apply for all PBMs would help address the problem, he said, and, with industry support, he would be willing to sponsor this.

Public Comment

Dr. Terry Meyer stated that he had come to ask support of the physician aid-in-dying lawsuit in New Mexico that will go to trial in December. Compassionate Choices is supporting

the physicians and patients. It was noted that this will be on the committee's agenda in Hobbs in October.

Bob Hearn, with Tierra del Sol, said he is trying to assist families who have emergency needs from flooding and fires. There has been emergency response, he said, but nothing to help meet the needs of folks in recovery after flooding. They need food and transportation, as their lives have been disrupted, but they are not in immediate danger and so they do not meet requirements for continuing aid. Catholic Charities is helping to move trailers, and any other assistance would be appreciated.

Josafina Mata, executive director of Contigo Campesino, an organization focused on community need in volunteer respite care, is a resident of Dona Ana County. She said she is here to support dental therapists and dental programs that address health disparities in rural areas.

Sandra Gonzales-White, a volunteer community health worker, said she came to express her support for dental therapists. Cost of dental care is high, and there is lack of access to dentists in rural areas, she said.

Kay Lilley, regional director of Progressive Residential Services in Dona Ana County, and Anna Otero-Hatanaka, executive director, Association of Developmental Disabilities Community Providers, said they wanted to share with the committee some of the changes with the developmental disabilities services and supports home- and community-based Medicaid waiver ("DD waiver"). In 2011, there was a five percent cut to providers and additional cuts for services, they explained, and this put DD waiver providers in the position of cutting both administrative and direct care staff. In May, rates and services were cut again. Now, agencies cannot pay enough to retain staff, and providers have been serving some clients for at least a year without getting paid. Despite inquiry, the providers have no idea why they have not been paid. After a 42 percent rate cut, many employment services have been discontinued. Ms. Lilley and Ms. Otero-Hatanaka are asking for support from the committee for positive changes in the DD waiver program.

Dental Therapy

Pamela Blackwell, J.D., project director for oral health access for Health Action New Mexico, a statewide health care consumer advocacy organization, said that New Mexico ranks thirty-ninth in the U.S. for the number of dentists per 1,000 population. Thirty-four percent of third graders have dental decay, she said, and very few dentists in New Mexico accept Medicaid. Poor oral health leads to absence from school and work and causes other health problems.

Ms. Blackwell is recommending the use of dental therapists, working as part of a team with a dentist, as a sustainable model in New Mexico that is cost-effective. This is a career and job opportunity for rural and tribal areas, where the need is greatest, she said. The federal Patient Protection and Affordable Care Act (PPACA) prohibits states from having dental therapists unless the state allows this scope of practice. In 2011 and 2013, legislation was introduced in

New Mexico with broad statewide support, but it did not pass. Legislation needs to include a career pathway for dental hygienists and needs to determine how to resolve the tribal sovereignty issue. This crisis will only get worse, Ms. Blackwell said. It requires action and a solution.

Frank A. Catalanotto, D.M.D., professor and chair, Department of Community Dentistry and Behavioral Science, University of Florida College of Dentistry, said dentistry visits to the emergency room have skyrocketed, with 800,000 visits across the country, 61,000 of these requiring hospitalization. Other patients are given antibiotics and pain medication and told to visit a dentist the next day. A new study reveals that 35 percent of lower-income high school seniors have not been to a dentist in four years, Dr. Catalanotto said, mainly because of cost. One in five children is in dental pain, according to the Florida study, and school performance suffers. This is now cutting across to the middle class, Dr. Catalanotto said, with a drop in the number of adults seeking dental care — again, mainly due to cost.

The dental therapy model is working in Alaska and Minnesota, Dr. Catalanotto said, and it is a great fit for New Mexico. Dental therapists are less expensive to educate and return to the community, he said, and the program is evidence-based, cost-effective and safe. A dentist with a doctorate is trained in about 500 competencies; dental therapists are trained in 90, with a major emphasis on prevention. Training more dentists is the most expensive solution, Dr. Catalanotto said. The best solution is this new work force model.

Sarah Wovcha is the executive director of Children's Dental Services in Minneapolis (see handout), the oldest nonprofit providing dental services in Minnesota. Her organization has quadrupled in size since 2000, now serving 30,000 people a year, Ms. Wovcha said, and it is the single largest provider in schools and Head Start centers. There are two types of new dental providers authorized in Minnesota: dental therapists and advanced dental therapists. These therapists are allowed to work remotely under the supervision of a dentist, leaving dentists free to perform more complicated care and increasing their productivity, Ms. Wovcha said. This was originally opposed by dentists in Minnesota, but now it has gained support from the dental community.

Terry Batliner, D.D.S., M.B.A., a dentist from Boulder who is associate director of the Center for Native Oral Health Research at the Colorado School of Public Health, spoke about oral health in tribal areas. According to an Indian Health Service (IHS) study, in the Navajo Nation, 60 percent of children two to five years of age have untreated tooth decay, he said. In the Pueblo of Santo Domingo, that rate also is 60 percent, and adults have even worse oral health. In multi-state Indian nations, the tooth decay rate for children is 70 percent. In order to change this, treatment must also include prevention, Dr. Batliner said, and the IHS has not done a good job at this. Excepting Alaska, Title 10 of the PPACA prohibits expenditure of federal dollars on dental therapy unless the state where the tribes reside makes dental therapy legal, Dr. Batliner said. "I ask for your help for native solutions for native communities."

Kathleen Bettinger, R.D.H., director of the interim dental hygiene program at Dona Ana

Community College, said she was speaking on her own behalf. Ms. Bettinger told members that she traveled to Alaska to visit dental therapy teaching programs in Anchorage and Bethel, and she was very impressed. Students come from communities that have mentored them, she said, and there is huge community support. The coursework has a very linear structure, and students are able to move ahead based on skills. They acquire a full scope of knowledge and gain clinical experience right from the start. Dentist supervision is strictly adhered to by phone or internet, and standing orders limit therapist services. Dentists are trained and supervised within their own peer group. The facilities in Alaska are modern and very patient accessible, Ms. Bettinger said.

Questions/Comments

Committee members had questions and comments on the following topics.

Length of training for dental therapists. This legislation would provide two paths: a dental therapist program requiring three years of training, or a registered dental hygienist completing intensive training for three to six months. "We want to give schools flexibility in how they set up their programs", Ms. Bettinger said. Minnesota and Alaska are the only two states that currently have dental therapists, but 15 other states are looking at it, she said. In Alaska, they must be recertified every two years; in Minnesota, there is no recertification, but each must complete continuing education requirements.

Use of telemedicine. "Could you have a supervising dentist at either UNM or NMSU supervising in real time?", a member asked. "Yes", Ms. Bettinger answered. This is a competency-based program, and a therapist must get prior approval from the supervising dentist for extractions. The dentist might be supervising up to four therapists. In Alaska, the dentist does get training in how to supervise therapists, Ms. Bettinger said. Telemedicine may also hold promise for orthodontia, where much of the adjusting already is being done by auxiliary personnel anyway, another member suggested.

Support for new dental therapy legislation. In response to a question about possible support from the Office of the Governor, Ms. Bettinger said that her group is working on that issue but is unsure of the governor's position. The New Mexico Dental Association (NMDA) is still opposed, noted another member; it says there are enough dentists in New Mexico, and it is not sold on the therapist concept. Ms. Bettinger said the group had several meetings with the NMDA and will continue to try to gain consensus. The New Mexico Dental Hygienists Association does support the hygienist-based model for therapists that is now being proposed, she said. Another committee member offered the opinion that using dental therapists is a good idea, but graduates should be required to go back into underserved areas for a period of service — and that this should be spelled out in the legislation — in order to get more buy-in from the dental community.

Federal funding and tribal sovereignty. There is a provision in the PPACA that if a state passes a law to permit the practice of dental therapy, federal grant money is available for training and education, Ms. Bettinger said. Community solutions need to be explored, said another

member, adding that the Navajo Nation is very interested in dental therapists, but federal funding must be available. The Alaska program, which has been studied extensively, has been working very well getting dental care into the rural communities where it is needed, Ms. Bettinger said.

Representative Madalena informed members that there is a video of what Alaska Natives have done with dental therapy, and he would very much like to locate it and bring it to the committee to be viewed.

Fluoridation and Water Supply

Rudy Blea, program director, Office of Oral Health, Department of Health (DOH), said that making sure oral health is just as important as medical and behavioral health is the goal of his office (see handout). Detailing the relationship between oral health and disease in New Mexico, Mr. Blea said that water fluoridation is an easy and relatively inexpensive preventive measure to combat tooth decay. Fluoride is natural and it is very effective, he said. Community water fluoridation is the adjustment of natural fluoride levels in public water systems to an optimal level to prevent tooth decay. Studies have found that every $1.00 invested in community fluoridation reaps $38.00 in savings from fewer cavities. Twenty-six of New Mexico's 33 counties are considering it.

The cities of Santa Fe, Farmington and Raton provide fluoridation of their water supplies, and Albuquerque has partial distribution of fluoridated water. He urges the legislature to promote community fluoridation throughout the state, he said. A public education media campaign is under way encouraging all New Mexicans to "drink water", Mr. Blea said, reminding committee members that oral health is essential to all health.

Motion for Letter Regarding Behavioral Health Statistics

It was moved that a letter be sent to the Behavioral Health Services Division of the HSD asking that the committee be provided with statistics on the number of clients being served by the 15 audited agencies two months before the takeover, and the same data for the new agencies as of today (September 5, 2013). The motion passed. A member asked that the committee review the letter, before it is sent, at its October meeting in Hobbs.

Another motion asked that a letter be sent to the chief executive officer of La Frontera requesting his attendance at the next committee meeting in Hobbs. This, too, passed unanimously.

Grant, Luna and Hidalgo Counties Inmate Support Program Pilot Project

Matthew Elwell, director of the Luna County Detention Center, and Mike Carrillo, director of the Grant County Detention Center, presented the committee with a plan for a pilot project (see handout) that aims to reduce the in-and-out jail cycle for the mentally ill. Creating a collaboration, as directed by House Joint Memorial 17 (2011), this program model will show that counties can save dollars and improve lives by providing a follow-up plan for when the inmate is released. Recent statistics show that 26 percent of inmates at detention centers are on psychotropic medications, Mr. Elwell said. Recently, a 27-year-old schizophrenic inmate spent

418 days in detention on misdemeanor charges. He is noncompliant and has no treatment guardian. "We need mental health counseling in our facility", Mr. Elwell said. Law enforcement is acting as treatment, and employees of correction centers end up becoming managers of the mentally ill. They need to be trained for the job, he said. These inmates also would benefit from coordinated case management and life skills development to increase success with community reintegration upon release.

Mr. Elwell and Mr. Carrillo told the committee that their proposal asks the legislature for $63,000 per year per county to fund a three-year pilot project. There are 29 jail facilities in the state, and cost savings and the success of inmates are the overarching goals of this collaboration.

Questions/Concerns

This group is probably all on board with the concept, said one committee member, but more detail is needed, especially on how to measure the data. Another member commented that it is terrible that being mentally ill is a crime. Far too much is being spent on things that do not work, she said. This is a classic example of how behavioral health costs get shifted, said another. It is a great project, the member said, but goals need to be quantified. The key to this will be aftercare and family involvement. Representative Madalena suggested that Mr. Elwell and Mr. Carrillo come back to the committee in November with actual legislation.

The committee recessed at 5:35 p.m.

<u>Friday, September 6</u> — Skeen Library, New Mexico Institute of Mining and Technology, Socorro

The meeting reconvened at 9:15 a.m. Representative Madalena greeted committee members and staff and then turned the gavel over to Senator Rodriguez, chair of the Disabilities Concerns Subcommittee, since the day's topics are of special concern regarding the disabled.

Recommendations for Sustainability of the DD Waiver Program

Ruby Ann Esquibel, principal analyst for the Legislative Finance Committee (LFC), and Pamela Galbraith, program evaluator, LFC, described the DD waiver program as one that offers a broad array of community-based services, in lieu of institutional care, to individuals with developmental disabilities. The DD waiver program is managed by the Developmental Disabilities Supports Division (DDSD) of the DOH and is administered by both the HSD and the DOH through a joint powers agreement. Medicaid waivers are granted to states from the federal Centers for Medicare and Medicaid Services (CMS) to allow them to provide home- and community-based programs for developmentally disabled individuals as an alternative to institutionalization.

The present budget situation, with increasing costs and a rapidly growing waiting list, requires action, Ms. Esquibel said. The most costly services are supported living, family living and day habitation. The legislature appropriates funding for the DD waiver program, which then becomes the basis for the Medicaid match. There are multiple regulations and two state

departments that administer the program and more than 300 providers critical to the delivery of services.

In fiscal year (FY) 2008, each DD waiver program client received $71,400 in services (see handouts) and was eligible for an additional $7,400 in regular Medicaid services, ranking New Mexico near the top 10 as one of the most expensive states in the country. A federal requirement is that the state's individual costs always be less than the institutional rate, which now stands at nearly $99,000, Ms. Esquibel said. The number of people on the DD waiver waiting list has risen from 3,700 in FY 2008 to nearly 6,000 in FY 2013, despite efforts by the legislature to move more people off the list and into the program. An LFC evaluation of the program in June 2010 (see handout) highlighted the unsustainable spending levels and the need for cost containment, Ms. Esquibel said. "We are growing the dollars but not the number of people being served", she said, and this is a "red flag".

The LFC report's recommendations to the DOH and HSD include, among others, finding an appropriate tool to evaluate enrollees and their service needs; conducting a study of services to determine if New Mexico rates are above or below other states; moving forward immediately with cost-saving strategies using information from stakeholders and this report; and validating financial data in managed care organization (MCO) spending reports. (Claims data for services provided to those on the waiting list were examined over a three-year period, and it was found that the MCOs received $91 million more than the cost of providing those services to this population.) Ms. Esquibel also mentioned the negative fiscal impact of the *Jackson* class action lawsuit, noting that the LFC report urges the DOH to develop and implement plans to meet outcome expectations and to submit semiannual disengagement progress reports on *Jackson* to the LFC and LHHS.

In 2011, the legislature appropriated an additional $1 million for FY 2012 to reduce the number of individuals on the DD waiver waiting list by approximately 50 people. In 2012, another $2.8 million was appropriated for the same purpose, reducing the number by about 150 persons. Despite this increased spending, the DDSD reverted $4.1 million to the general fund for FY 2012 and $2.8 million for FY 2013 and made only modest increases to clients served by the DD waiver.

Questions/Concerns

Members discussed these findings and had questions on the following topics.

Problems with HSD data. A committee member wondered why no "credible allegation of fraud" has been made against the MCOs that received $91 million more than the cost of services they delivered. Ms. Galbraith responded that the HSD reports that it does not use claims data to determine whether amounts paid to MCOs are sound. The HSD provided data, she said, but there were huge discrepancies. Another member asked how the legislature is supposed to make good decisions if it does not have good data. Apparently, the MCOs had a problem accurately reporting their administrative costs, Ms. Galbraith said. There may be reasons for those discrepancies, but they were not explained. The committee member noted that service agencies

have been closed down by the HSD, and they apparently do not have the same rights that state government has to address "apparent discrepancies".

Reversion of nearly $7 million to the general fund. There is a waiting list with 6,000 people on it, one member noted. "Do we know who needs what?", he asked. Ms. Galbraith responded that some needs may be known. The DOH has told the committee that it knew these needs, the member said, but it appears that the state is in the same boat as it was seven years ago, dealing with the same issues and with clients not having their needs met. "Are some individuals on the waiting list getting Medicaid services?", Ms. Galbraith was asked. She responded that claims data are available for those getting Medicaid services, but there must be a needs assessment for those on the waiting list. The LFC recommended that the most disabled persons be evaluated first and that assessments be made for the most critical applicants.

New enrollment in the DD waiver program from the waiting list "has not met legislative intent", a member observed. Ms. Galbraith concurred that appropriated funding has gone unused. "We are here for policy", the member noted, "and it's not about funds; that's not the problem. The problem is that they (DOH) are not spending what has been appropriated.".

Cuts to provider services. As a parent of a child on the DD waiver, a member told the rest of the committee that no one trusts what will happen next. "You could get a letter tomorrow that says your services will be cut in half, or that you have to choose between types of therapy, and which is the most important? Cost containment is certainly not painless." The member also told of friends who had to quit their jobs to stay home and care for a developmentally disabled family member. The committee member pointed out that some of the individuals sitting in the audience, several of whom have earned college degrees, would have been institutionalized in the past. "Even if there are less dollars, the quality of life in a community-based setting is priceless." Another committee member concurred. Rural New Mexico is being hit the hardest when there is talk about how much is being cut back. "If society can't take care of its most vulnerable, then who are we?", she asked.

Community Provider Panel on Developmental Disabilities Programs and Services

Ms. Otero-Hatanaka described the impacts of the redesign of the DD waiver program (see handout). The purpose of the redesign is to save money, she said, by reducing services to individuals currently in the DD waiver system in order to fund services for persons on the waiting list. Among the many changes that took place May 1 is the use of a new assessment tool, the Supports Intensity Scale (SIS); implementation of new service packages that reduce the number of hours of care an individual can receive for certain critical core services; and rate reimbursement cuts for core services, per recommendations made by an out-of-state survey contractor, Burns and Associates. Some providers have reduced their services, others have closed their doors and there will be more agencies closing down because of quality assurance issues, Ms. Otero-Hatanaka said. "The community structure is being dangerously eroded."

Lisa Cisneros Brown, a speech-language pathologist who is representing therapists statewide, is an agency administrator and direct caregiver and was part of the team that met with

Ms. Galbraith during her research for the LFC report. The adverse impact of SIS standards is a drastic reduction of services, Ms. Brown said. New Mexico sent dollars elsewhere for administering the SIS and for the Burns rate study, which was so complicated that agencies needed help in order to respond. Now the state is paying $800 per SIS assessment, and there are many requests for reassessments, she said. Ms. Brown gave examples of an individual who cannot speak having been evaluated for less care and more time alone; of an interpreter who participated for four hours of SIS, but the test actually took more than six hours; and of a team member who stopped the evaluation because of interviewer rudeness to her client. Seventy percent of those who have a reassessment get a different score, Ms. Brown said. Placement in an A, B or C category means the client can have only one therapist, and family members must choose between the risk of their loved one falling or choking (aspiration choking can cause pneumonia and death).

Arlene Lindsey is manager of the DD waiver program, Tresco, Inc., which has been in existence for 45 years and now serves 140 individuals under the DD waiver program. There has been much discussion about the SIS, and Ms. Lindsey gave committee members an example of a recently-assessed consumer. He is on the DD waiver, lives at home and has health problems and depression and uses a cane and a walker. He has been getting 36 hours of assistant care, including nursing oversight of health care plans, travel to Albuquerque to see a specialist, meal preparation and help with finances and multiple medications. Just to manage his medications requires 14 hours a week, she said. With the new assessment, he will not have enough hours to even address his medication needs. Ms. Lindsey asked the committee, "Who will be responsible for this client?". She was told that her agency is responsible, even if it is not permitted to provide appropriate services.

Questions/Concerns

A member asked if individuals in "supported employment" are required to be paid minimum wage. Ms. Galbraith, from the audience, responded that there is an exemption from the federal minimum wage, and unfortunately, that sends the message that you are not a "real" worker. Goodwill Industries has decided that it will no longer participate with the state on employment because the rates are so low, said another member. DD providers may be "next on the chopping block".

Therapists are leaving the DD waiver for moral reasons, a member said. Ethically, they cannot just provide care for one hour a month. This population has a target on its back, Ms. Otero-Hatanaka said. Our system is crumbling, she said. People really need to know what is going on. It has been a double whammy, with a new rate system and cuts. Rates for providers need to be raised, not cut, she said. A member asked how much was needed to properly support community providers. Any increase would help, Ms. Otero-Hatanaka responded; it has been 10 years since they got a raise.

Legislators need to request the LFC to do more analysis and number-crunching, so there can be better comparative figures of what is going on in other states, a member said. Then there would be a baseline, and intelligent figures could be plugged in. It is almost like ignorance is

bliss, he said. Another member commented on cuts to supported employment. In the *Jackson* lawsuit, the state is being hammered for not enough of it. Why this disparity?, he asked.

Consumer Perspectives on SIS Assessments and Other Issues

Doris Husted, director for public policy at The ARC of New Mexico, said she was here as the consumer voice of those who have had SIS assessments.

Adam Shand told committee members he is very excited to be part of a pilot group of 500 to take the SIS. He took the test with his mother, who is his home-based provider, but he has asked for a reassessment. "I am very capable with technology, but I do need help physically", he said. "I have been blessed with a strong voice, and I use it to advocate." Mr. Shand said that everyone should band together in advocacy to help individuals reach their full potential. "We are all just people, and we are all in this together."

It was noted by a committee member that Senator Candelaria has recognized Mr. Shand's work as a self-advocate on the senate floor.

Vicki Galindo is the parent of a Down syndrome child who took the SIS assessment in June after weeks of her parents' preparation. Ms. Galindo said she had heard a lot of negative stories about the SIS and knew that the person who would conduct the assessment "literally had our daughter's future in her hands". There were a lot of good people at the assessment, she said, including her daughter's case manager. It took about an hour and a half, and the results came in about three weeks.

Amira Rasheed had team members who helped her prepare — her physical therapist, case manager and the coordinator of services. "I fall into a lot of gray areas on the SIS, which took about two hours, but hopefully I can get a letter that agrees, and will provide the services I need." Ms. Rasheed holds two college degrees and is working toward a master's degree.

Robert Kagel, parent advocate, said he has appeared as an expert witness in federal and state court. The results of his son's first SIS were "ridiculous", he said. After complaining to the DDSD, his son went from D to F; he is severely disabled and requires assistance with 99 percent of his needs. Now his son just got his group H evaluation, and Molina Healthcare got approval to provide services last week. Mr. Kagel said two of his son's providers have not been paid, and two of them said they are quitting the DD waiver program.

Mr. Kagel said that the reason other states can provide DD care cheaper than New Mexico is because they have private institutions or large numbers of intermediate homes. Who are these Burns people?, he asked, referring to the rate study. Mr. Kagel is highly critical of the Burns study and what he calls the bogus use of the sole-source SIS. Federal law provides public input whenever the waiver is changed, Mr. Kagel said. The task force members are mostly from Albuquerque, and they had only one meeting. "Then they did statewide dog-and-pony shows, sent letters to providers and families, then put some small thing on their web site", Mr. Kagel said. Total comments for the entire year, including work force and 10 regional meetings, were 24

from individuals, and only two comments on the SIS, he said. Task force members were not told that the game plan was to kick people off Medicaid residential services, Mr. Kagel said. New services include crisis support, but no providers are listed who provide crisis support; they say they will not touch it. Providers have no idea what their income will be over the next year and no idea who will be getting what services, Mr. Kagel concluded.

Public Comment

Mike Kivitz commented on additional reasons for the disparity in New Mexico's higher DD waiver costs, besides those cited by Mr. Kagel. Policy decisions, such as having only three to four individuals in a group home, and $75 million to support families drive up the individual total cost of services. The rates to providers do not need to be cut, said Mr. Kivitz, who is president and CEO of Adelante, an Albuquerque DD waiver provider. "The board of my agency is meeting now to figure out how to cut $1.5 million from Adelante's budget by reducing retirement and benefits for staff."

Pam Lillibridge, who holds a master's degree in public administration, said that the important theme is having clients able to get what they need. "There is a big gap between the SIS and our opinion", she said. "You don't promote independence by taking everything away." She said her agency, Tresco, in Socorro, is still considered responsible even if it is not paid to deliver appropriate services.

Jessica Valmeister is the parent of a disabled child and spoke of the lack of acute crisis facilities that will accept children with fragile medical conditions and behavioral health issues. When her son was in crisis, there was nowhere to take him, and emergency room personnel suggested a voluntary surrender of custody to the CYFD for respite care and some kind of treatment. She had been to multiple state levels and had even gone to the media for help. There was just nowhere for children like hers to go, she said. Her son died last year.

Jim Jackson, executive director of Disability Rights New Mexico, said he had notes about the *Jackson* case, in which his organization is involved, and is experiencing the same frustrations as the legislature. He feels that *Jackson* benefits others in the DD waiver community, not just *Jackson* class members. Mr. Jackson also feels there is a serious leadership issue and low level of commitment within the DOH and is frustrated with the reversion of nearly $7 million. What will it take to get the DOH to commit to take folks off the waiting list?, he asked. The SIS is not a professional evaluation as to therapy needs, Mr. Jackson said. An entire category for individuals with the most serious needs has evaporated.

Brian Tierney, a partner in Direct Therapy Services in Las Cruces, supports most of what has been said. There are severe delays in budgets and payments. Billing and approval of payments are a serious problem. There is money being transferred back that should instead be applied to bills that have not been paid before the end of the fiscal year, he said.

Lori Rossburn, a speech-language pathologist, said that with all of the people being flown in from Arizona and Canada, what the state is taking away from services is criminal. "It is

unconscionable what is being done here. We pay tons of money to Molina to not pay our bills, and not approve our budgets", she said. "Clients ask, why are they doing this? Tell them to stop! We serve at the will of the department, and other therapists are afraid to come here", she said. "People we love and serve are getting hurt."

Tammy and Stuart Melloy live in Albuquerque so their daughter can get the care that she needs. Their daughter is on 100 percent total care, with a feeding tube, epilepsy, diapers and chronic respiratory issues. She scored an F on the SIS assessment and will lose two-thirds of her therapy hours. She has been using 14 hours of therapy a month but now will have just 30 therapy hours for the entire year. Ms. Melloy is her daughter's caregiver, and she gets 750 hours of substitute care and wants to know why she cannot use the dollars from substitute care and apply them to therapy. This new package of care is not individualized at all, Ms. Melloy said.

Cathy Stevenson, director of the DDSD, who was sitting in the audience waiting for her own presentation, stood and said she would follow up on the Melloy case.

Peggy Denson, director of Zia Therapy Center in Alamogordo, noted that the state has been increasing the expense but not increasing the number of persons served on the DD waiver. Providers' expenses are growing, but their bottom lines are going down. The average cost per consumer has decreased, and now there is a wide margin between that and the cost of institutionalization. These cuts are on the backs of the consumers and the providers, she said. There is a crisis of staffing, and qualified folks cannot be attracted or retained. Implementation of the new DD waiver has been delayed and delayed, and this has wrecked any opportunity to plan or budget. Every SIS only tells part of the financial story. Just wait until January 1, when there is Medicaid expansion and PPACA expenses increase dramatically, she warned. The center's owners are talking about the possibility of downsizing Zia.

Barbara House, whose daughter is one of the original children at the Zia Therapy Center, said she has received a letter from a person who needs full care but who now must go out in the community to get services and another letter from a person who has a son in a wheelchair and must go out in the community to get services as well. We are headed backwards, she said.

Kent House, Ms. House's son, spoke of his disabled sister, who is 57 years old, and how his parents worry about what is going to happen to her. The system is crashing now, he said, and families have to become involved. Services are not being delivered in an honest and trustworthy way. The SIS is not an honest test; it is not right, Mr. House said.

Nannie and Rosemarie Sanchez said the purpose of the DD waiver is to provide services, and they then read a statement: There is a lack of agencies that provide person-centered services, and information is not being provided to families of the disabled. The Sanchezes would like to join with two Democrats and two Republicans who are pushing for a citizens oversight and review committee.

Sustainability of the Developmental Disability System

Peter Cubra, an Albuquerque attorney and advocate for people with developmental disabilities, described how he came to his professional interests. He was raised with a cousin who was born with profound cognitive disabilities, and his dad would always say to him, "There, but for the grace of God, go you.". Mr. Cubra subsequently became a special education teacher in Michigan. In the 1970s, disabled people in Michigan came out of institutions and into the community, and Mr. Cubra's concerns about the resulting "mess" was what propelled him to law school. When he came to work in New Mexico, he and Mr. Jackson decided they were going to try to get people here out of the institutions and into the community. In 1987, they filed suit against the state because there was not a community system sufficient to meet the needs of the disabled.

Federal Judge James A. Parker is a cautious, conservative judge, Mr. Cubra said, but they were able to convince him that there was discrimination against the disabled, and in 1990, Judge Parker ruled in their favor. The fact that the goal of the lawsuit has not yet been accomplished is why the case is continuing, he said. In October 2012, the court again ruled in their favor on 99 of 104 alleged violations of the agreement with the state in the areas of health care, safety and meaningful employment for those who want it. A compliance administration now has been set up, and Dr. Sue Gant has been authorized by the judge to help craft plans that are clear and specific, and, hopefully, to bring this case to an end.

"Our community system is once again discriminating against these people", Mr. Cubra said. The SIS is slamming people into the wrong category at an alarming rate, and many people are afraid to retest and be stuck with the score. The *Jackson* class has been exempted, a tacit acknowledgment that people will not get what they need, Mr. Cubra said. This system is deteriorating because of the SIS, he said. "My clients will not be able to get the services they need, and they are entitled to services that do not exist."

Mr. Cubra said he appreciates why payment of attorney fees in *Jackson* is a concern for the taxpayer in New Mexico, but those are negotiated rates, he said, two-thirds of normal rates. A committee member noted that the state had just signed a contract with an Arizona provider for $300 per hour, more than Mr. Cubra's hourly rate. There are 10,000 people either receiving services on the DD waiver or waiting to receive services, Mr. Cubra said. The question is: Are we going to pony up to help these 10,000?

Questions/Concerns

A member asked what is the obstacle to closing this lawsuit so those funds can be used to service New Mexicans. Ms. Stevenson strongly defended the state's efforts to satisfy its obligations for the 23-year-old lawsuit. "The bar continues to rise", she said. Another member asked Ms. Stevenson about the reversions of nearly $7 million to the general fund. The money does revert, she said, but it will need to remain in the base. Sometimes it is not reallocated. That money is tied to a person, Ms. Stevenson said. It is given to the division for line-item services.

Status and Funding of SIS Activities

Ms. Stevenson introduced Cristina Hill, who described the SIS assessment (see handout). The interview is face-to-face, Ms. Hill said, and the results of the assessment are group assignments. The current number of individuals assessed who are requesting a retest is 20 percent, she said, and 70 percent of those are being reassigned to a different category.

Molina Healthcare was the focus of another member's question. He asked for numbers on the bills that have been submitted by providers but have not been paid in the last six months. The member also asked for information on which services are being denied and said that the SIS uses some kind of algorithm that is not published. It is available, Ms. Stevenson countered; it is not published, but it has been distributed.

Concerns about Canadians coming into New Mexico to administer the assessment were also discussed. Can we train New Mexicans?, a member asked. Ms. Stevenson said that trained and certified assessors seemed important, rather than using a trainee. "Since this is such an important life-changing decision, we felt we needed an experienced interviewer."

Another member expressed serious concerns about liability for therapists. He asserted that the SIS is being used to decide therapies. Another member urged Ms. Stevenson to bring a thorough breakdown of the amount of general funds allocated to the waiver to the next meeting. This committee is looking for solutions, he said.

Ms. Stevenson's explanation of the reversion was clear, a member told her, but why is there so little increase in the number of those served? Ms. Stevenson said she would have more information at the next committee meeting.

The committee adjourned at 5:30 p.m.